Implications for Rehabilitation

- The Activities and Participation component of the Comprehensive ICF Core Set for OPD is largely supported by the perspective of patients with COPD and therefore could be used in the assessment of patients' individual and social life.
- The information collected through the Activities and Participation component of the Comprehensive ICF Core Set for OPD could be used to plan and assess rehabilitation interventions for patients with COPD.

Comprehensive ICF Core Set for Obstructive Pulmonary Diseases: validation of the Activities and Participation component through the patient's perspective

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Abstract

Purpose: This study aimed to validate the Activities and Participation component of the Comprehensive International Classification of Functioning, Disability and Health (ICF) Core Set for Obstructive Pulmonary Diseases (OPD) from the patient's perspective.

Methods: A cross-sectional qualitative study was conducted with a convenience sample of outpatients with Chronic Obstructive Pulmonary Disease (COPD). Individual interviews were performed and analysed according to the meaning condensation procedure.

Results: Fifty-one participants (70.6% male) with a mean age of 69.5±10.8 years old were included. Twenty-one of the 24 categories contained in the Activities and Participation component of the Comprehensive ICF Core Set for OPD were identified by the participants. Additionally, 7 second level categories that are not covered by the Core Set were reported: complex interpersonal interactions, informal social relationships, family relationships, conversation, maintaining a body position, eating and preparing meals.

Conclusions: The Activities and Participation component of the ICF Core Set for OPD was largely supported by the patient's perspective. The categories included in the ICF Core Set that were not confirmed by the participants and the additional categories that were raised need to be further investigated in order to develop an instrument according to the patient's perspective. This will promote a more patient-centred assessments and rehabilitation interventions.

Key words: Chronic Obstructive Pulmonary Disease; International Classification of Functioning, Disability and Health; Activities and Participation; Patient's perspective.

Introduction

Currently, Chronic Obstructive Pulmonary Disease (COPD) affects 210 million people worldwide and it is projected to be the seventh leading cause of years lived with disability by 2030[1,2]. COPD is a progressive condition that can severely affect patients' physical, psychological and social dimensions of life[3,4]. As a disabling condition, adequate knowledge about the health and functioning of patients with COPD is crucial to design appropriate rehabilitation interventions for this population.

The World Health Organization (WHO) have recommended the use of the International Classification of Functioning, Disability and Health (ICF) to comprehensively assess the health experience of patients suffering from specific health conditions[5]. The ICF reflects the biopsychossocial model in a unified and coherent view of various dimensions of health (biological, individual and social) and allows the establishment of a standard language for describing health[5,6]. However, since the ICF is designed to record and organise a wide range of information about health, containing over 1400 categories[5], practical tools, such as ICF Core Sets, have been developed[7]. Core Sets represent a selection of ICF categories describing the prototypical spectrum of problems in functioning of patients with a specific health condition[7]. For Obstructive Pulmonary Diseases (OPD), where COPD is included, two types of ICF Core Sets have been developed: the Brief and the Comprehensive[8]. The Brief Core Set, a shorter version of the Comprehensive, is composed by minimum data to be used at any clinical encounter[7,8]. The Comprehensive Core Set has the ability to collect more information and it is indicated to guide multidisciplinary assessments in the rehabilitation process[7,8]. The current version of the Comprehensive ICF Core Set for OPD consists of 71 categories, 19 of which assess the Body functions, 5 the Body structures, 24 the Activities and Participation and 23 the Environmental factors[8]. Since the ICF is useful in structuring the rehabilitation process, which one of the main goals is to overcome activity limitations and participation restrictions[9], the Activities and Participation component is the most represented in the Comprehensive ICF Core Set for OPD[8]. However, the selection of the Activities and Participation categories included in the ICF Core Set was performed by health professionals and may not express the living experience of patients with COPD[8,10,11].

The WHO also advocates a patient-centred care model, where patient's expectations, needs and preferences are considered in health and social care planning[12]. Therefore, it is imperative to analyse if the current version of the Activities and Participation component of the Comprehensive ICF Core Set for OPD allows the assessment of the most significant limitations and restrictions experienced by patients in their daily life, according to their own perspective.

Thus, this study aimed to contribute to the validation of the Activities and Participation component of the Comprehensive ICF Core Set for OPD considering the perspective of patients with COPD. Specifically, the study aimed (i) to explore the aspects of activity limitations and participation restrictions which are relevant to patients with COPD and (ii) to examine to what extent these aspects are represented by the Activities and Participation component of the current version of the Comprehensive ICF Core Set for OPD.

Materials and Methods

Study design

A cross-sectional qualitative study, using individual interviews, was conducted with a convenience sample of outpatients with COPD. The study received full approval from the Ethics Committees of the Portuguese Center Health Regional Administration and of the São Sebastião Hospital.

Subjects

The sample was recruited from December 2010 to October 2011 in the central region of Portugal. Participants were included if they: i) were diagnosed with COPD (International Statistical Classification of Diseases and Related Health Problems (ICD-10) codes J44, J45) according to the Global Initiative for Chronic Obstructive Lung Disease (GOLD)[3]; ii) were ≥ 18 years old; iii) were able to understand the purpose of the study and voluntarily consent to participate. Participants were excluded if they presented severe psychiatric conditions and/or inability to understand and co-operate.

Data collection

Participants were identified by the clinicians of the institutions involved in the study, two primary care centers and one district hospital. The researchers contacted via telephone all the potential eligible participants, explained the purpose of the study and asked about their willingness to participate. When patients agreed to participate, individual interviews were scheduled. Written informed consents were obtained prior to any data collection.

Socio-demographic (gender, age, education level and occupation situation) and clinical (lung function and COPD grade according with GOLD classification) data were first collected and then an individual interview was conducted. The interviews were guided by two open-ended questions that were formulated around functioning in daily life. Specifically, patients were asked about i) the impact of COPD on their life, "*Which are the main changes that COPD brought to your personal and family life?",* and ii) the major difficulties experienced in their daily life due to the disease, *"Which are the main difficulties that you are currently experiencing due to COPD?"*. All interviews were digitally audio-recorded and transcribed.

Data analysis

Descriptive statistics were first used to analyse the socio-demographic and clinical characteristics of the sample.

The qualitative analysis was performed by two independent researchers trained in the ICF and was based in the meaning condensation procedure[13], following three specific steps: i) the transcripts were read until researchers were intimately familiar with its content; ii) the data were divided into meaning units (considered as words, sentences or paragraphs containing aspects related to each other through their content and context), and the theme that dominated a meaning unit was determined[14]; finally iii) the concepts contained in the meaning units were identified, since a meaning unit could contain more than one concept. The identified concepts were then linked to the ICF categories based on established linking rules[15,16]. These linking rules have been firstly developed to link health-status measures to the ICF in a systematic and standardised manner, however, they have also been used in the validation process of other ICF Core Sets, such as rheumatoid arthritis[17] and diabetes mellitus[18]. According to these linking rules, researchers linked each identified concept to the ICF category which represented the

concept most precisely[15,16]. When a meaning unit contained more than one concept, it was linked to more than one ICF category[15,16]. If an identified concept was not sufficiently specified to decide about which ICF category to link, the concept was coded “nd” (not definable) and if a concept was not represented by the ICF, the concept was labeled “nc” (not covered)[15,16]. All problems mentioned by participants were considered relevant and treated as equal, therefore a quantitative analysis of categories (i.e., frequency of each category) was not performed[19].

An ICF category of the Activities and Participation component of the Comprehensive ICF Core Set for OPD was regarded as confirmed, if the identical or a similar category emerged from the interviews. Since the ICF categories are arranged in a hierarchical system, the second level categories of the Comprehensive ICF Core Set for OPD were also considered confirmed when the corresponding third or fourth level category had been identified.

To determine the consistency of the qualitative analysis between the two researchers, an inter-observer reliability analysis using the Cohen’s kappa was performed for each level of the ICF classification[20]. Fifteen percent of the qualitative analysis was randomly selected to perform this test[17]. The value of Cohen’s kappa ranges from 0 to 1 and can be categorised as: slight agreement (0.0-0.20), fair agreement (0.21-0.40), moderate agreement (0.41-0.60), substantial agreement (0.61-0.80) and almost perfect agreement (≥0.810)[21]. All statistical analyses were performed using PASW Statistics (Version 18.0, SPSS Inc., Chicago, IL).

Results

Sample characterisation

A total of 58 patients were approached for inclusion in the study, however 7 did not want to participate as they did not feel the study as being relevant. The response rate was 87.9%. Fifty-one participants (male n=36; 70.6%) were included in the study. Participants mean age was 69.5±10.8 (ranged from 44 to 88) years old. Most of the participants were married (n=40; 78.4%), had finished the primary school (n=33; 64.7%) and were retired (n=40; 78.4%). Their mean forced expiratory volume in one second (FEV_1) percentage predicted was 48.4±20.1 (ranged from 16 to 94). According to the GOLD criteria, 20 (39.2%) participants had mild to

moderate COPD and 31(60.8%) severe to very severe. The socio-demographic and clinical characteristics of the participants are summarised in table 1.

Insert table 1 about here

Inter-observer agreement

The inter-observer agreement between the two researchers was substantial for the ICF component, with Cohen's kappa of 0.714 (95% CI 0.340-1), and almost perfect for the second and third level, with Cohen's kappas of 0.958 (95% CI 0.878-1) and 0.935 (95% CI 0.812-1), respectively. Regarding the ICF chapter, the two researchers had perfect agreement, Cohen's Kappa of 1.

Activities and Participation ICF categories according to the participants' perspectives

A total of 125 relevant concepts were identified. These concepts were linked to 54 ICF categories of the Activities and Participation component, 15 from de second level and 39 from the third level, as shown in table 2. However, considering just the second level of the ICF classification, a total of 27 second level ICF categories of the Activities and Participation component were identified, as 12 new ones resulted from the correspondence of the 39 third level ICF categories (table 2).

Insert table 2 about here

Moreover, some identified concepts (n=5) could not be linked to the ICF. Two concepts were defined as "not covered", walking fast and falls, and three were labelled as "not definable", well being, work and effort.

Almost all (n=21; 87.5%) ICF categories included in the Activities and Participation component of the Comprehensive ICF Core Set for OPD were confirmed by the participants. Only the categories d465 moving around using equipment, d470 using transportation and d910 community life, could not be confirmed.

Seven additional second level ICF categories that are not included in the Activities and Participation component of the Comprehensive ICF Core Set for OPD were identified by the

participants' perspective (table 2). Most of the additional ICF categories were derived from the chapter Interpersonal interactions and relationships, d720 complex interpersonal interactions, d750 informal social relationships and d760 family relationships. The other 4 categories were related to activities such as conversation, maintaining a body position, eating and preparing meals. Thirty-eight third level ICF categories, that are also not included in the ICF Core Set, emerged and were mainly related to i) changing basic body position (lying down, squatting, kneeling, sitting and bending), ii) lifting and carrying objects (carrying in the hands, in the arms and on shoulders) and iii) doing housework (washing and drying clothes, cleaning cooking area and utensils, cleaning living area and using household appliances).

Discussion

This study identified a wide range of activity limitations and participation restrictions experienced by patients with COPD. Almost all concepts that were raised from the participants' interviews could be linked to the unified and standard language of the ICF. This finding demonstrates that the ICF comprise the broad spectrum of restrictions that patients with COPD experience in their daily life. Nevertheless, two identified concepts, falls and walking fast, were not covered by any specific ICF category. This highlights the ICF limitations: first, falls are not included in the ICF classification, despite being considered a worldwide major issue affecting older adults[22] and being shown by recent evidence that patients with COPD have a high susceptibility to fall[23]; secondly, even when the individual experience is included, such as walking (d455), this may not be with the level of specification required (walking fast). This limitation was previously reported by Kirchberger et al (2009)[18].

The current version of the Activities and Participation component of the Comprehensive ICF Core Set for OPD was largely confirmed by the participants' perspective. The category d465 moving around using equipment did not emerge in the participants' report. Ewert et al. (2004), in a study where the ICF checklist was used to identify the most common problems in patients with chronic conditions, also found that only 14.9% of patients with COPD experienced restrictions in moving around using equipment[10]. It might be hypothesised that this activity was not a significant issue on participants' daily life because it is only applicable for patients who use devices to facilitate moving, and even when it is applicable, some patients might see these

devices as facilitators, and therefore, they do not feel restricted when they are moving around. Despite the reported limitations on driving and driving human-powered transportation, being driven (d470 using transportation) was not reported as a restricted activity. In the literature, the restriction in this activity is not frequently reported. However, in the physicians' perspective (39% of agreement using the Delphi technique) this category is relevant to assess in patients with COPD[24]. Similarly, restrictions and limitations in community life, have not emerged in the participants' interviews. In the study of Ewert et al., community life was also not a relevant problem for patients with COPD, with a prevalence of 22.9%[10]. This might be explained by the patients' lack of involvement in charitable organisations, service clubs or professional social organisations, and thus, the participation in these activities is not considered as one of the most relevant problems for them. As these three categories were not confirmed by the participants' perspective, its maintenance in the Activities and Participation component of the Comprehensive ICF Core Set for OPD must be further discussed to understand if they really belong to the group of the most significant limitations and restrictions experienced by patients in their daily life and therefore are worthwhile to assess.

However, some additional categories, which are not currently included in the Activities and Participation component of the Comprehensive ICF Core Set for OPD, were identified. Three of these additional ICF categories were derived from the chapter Interpersonal interactions and relationships (d7). The category d720 complex interpersonal interactions was reported in the participants' interviews as mostly related with the difficulties in regulating emotions and impulses when interacting with other people. Probably the emotional disruption, including feelings of anxiety, depression and anger[25], characteristic of patients with COPD affects the way patients interact with others. In addition, participants referred having their participation in informal social relationships restricted, namely their relationships with people living in the same community. This restriction, which is well documented in the literature[26,27], was highly associated with participant's difficulties in moving out of their homes. The current version of the Activities and Participation component of the Comprehensive ICF Core Set for OPD does not provide any reference to the patients' family relationships (d760). However, in the participants' perspective, the disease impacted considerably in their family relationships. It is known that due to the COPD, patients frequently see their role within the family altered, which affects the

harmony of family relationships[28,29]. All these three ICF categories are consistent with the well-known spectrum of restrictions of patients with COPD. Thus, the inclusion of these categories in the Activities and Participation component of the Comprehensive ICF Core Set for OPD should be considered to fully cover the restrictions in interpersonal interactions and in relationships experienced by patients.

Further identified topics, but not included in the Comprehensive ICF Core Set for OPD, were related to activities such as conversation, maintaining a body position, eating and preparing meals. Conversation with one person was a restriction that participant's experienced, which was mainly related with the severity of their symptoms, especially dyspnoea. Another category of the chapter Communication, d330 speaking, is already included in the ICF Core Set[8] and it refers to producing oral messages with literal and implied meaning[5]. On the other hand, the category conversation includes the interchange of thoughts and ideas by speaking with other people[5]. Therefore, it might be more appropriate to include in the Comprehensive ICF Core Set the category conversation, since it expresses patients' speaking restrictions while interacting with other people, than the category speaking, as it only refers to the speech production. Maintaining a body position, specifically a lying position, was also reported as a limited activity. It is well document in the literature that in patients with COPD supine positions are associated with dyspnoea[30]. Both difficulties in eating and preparing meals were reported by participants. These activities are commonly assessed in patients with COPD with different activities of daily living scales[31,32]. Therefore, these additional categories also need to be further investigated to determine if they are relevant to include in the Activities and Participation component of the Comprehensive ICF Core Set for OPD.

It is important to emphasise that the participants expressed their significant limitations and restrictions with a high level of specification, that were mainly linked to third level categories of the ICF classification (n=39). However, only one of these third level categories is included in the current version of the Activities and Participation component of the Comprehensive ICF Core Set for OPD, which is the category d4750 driving human-powered transportation[8]. The others categories, are not directly included in the ICF Core Set, but are represented by corresponding second level categories. For example, the categories walking short distances, walking long

distances and walking on different surfaces emerged from the participants' reports, but in the current version of the ICF Core Set they are represented by the second level category, walking[8]. Nevertheless, when classifying a restriction using the second level categories, relevant information might be lost[33]. Therefore, the inclusion of some third level categories might be valuable for the patients' assessment and for the adequate planning of future health and social care interventions, hence, this needs to be further explored.

Strengths and Limitations

This study only validated the Activities and Participation component of the Comprehensive ICF Core Set for OPD since it is the ICF component that enables to collect more relevant information to plan a rehabilitation intervention for patients with COPD[6], and at the same time, that allows the assessment of the direct impact of that intervention in patients' individual and social daily life. Nevertheless, despite the crucial importance of this ICF component, it would be interesting to validate according to the patient's perspective also the other three ICF components: Body functions, Body structures and Environmental factors.

Focus groups using an ICF-based approach had been used in the validation of ICF Core Sets from the patient's perspective[18,34], since it was shown that this methodology identified more ICF categories than focus groups using an open approach or individual interviews[35]. However, this is not surprising as in the qualitative ICF-based approach, the titles of the ICF chapters are presented to the participants[17,18] and therefore can lead them to name problems, that spontaneously would not be raised. Also in focus groups, participants' statements can be greatly influenced by the group processes[36], and not reflect their true perspective. Therefore, these raises questions about how much of those categories are effectively representative for patients. The use of individual interviews with an open approach is a strength of this study, because even if less ICF categories had been identified in comparison with a focus group methodology using an ICF-based approach, it is believed that the ones identified are the most representative for patients' daily life.

To ensure the trustworthiness of the qualitative analysis, two main strategies were used: all interviews were conducted by the same researcher and the data was independently analysed

by two independent researchers. It is believed that these procedures have reduced the impact of any potential bias of the results. The inter-observer agreement, regarded as almost perfect for the component, second and third level of the ICF classification and perfect for the first level[21], was higher than other studies[17,18].

Regarding the sample of this study, two main limitations can be raised. Firstly, only Portuguese patients were included and patients in other countries may experience different limitations and restrictions in their daily life due to cultural reasons. Secondly, only patients with COPD were included, but COPD is a sub-type of OPD, and may not be representative of all OPD conditions. In order to overcome these limitations, similar studies could be conducted in other countries or cultures and with patients with other OPD. Other potential limitation of this study may be related to the linking process, since it was performed by a physiotherapist and a gerontologist. It can be hypothesised that health professionals with other backgrounds would have decided differently. Therefore, future studies should include other health professionals in the linking process.

Conclusions

This study comprehensively explored the activity limitations and the participation restrictions relevant to patients with COPD using a qualitative design. It was possible to verify that the structure of the Activities and Participation component of the Comprehensive ICF Core Set for OPD was largely supported by the patient's perspective. Nevertheless, more research is needed, specifically on the categories included in the ICF Core Set that were not confirmed by the participants' perspective and on the additional categories that were raised, to further validate the current version of the Comprehensive ICF Core Set for OPD or even create a specific ICF Core Set for COPD. This will allow the development of an instrument that integrates the full perspective of patients with COPD and therefore, a patient-centred assessment and planning of adequate health and social interventions. This study also highlighted some limitations of the ICF that may be considered in future revisions of this classification. Therefore, this study provides contributions for the decision on the final version of the Comprehensive ICF Core Set for OPD and on the ICF.

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Declaration of interest

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Table 1 - Socio-demographic and clinical characteristics of the participants (n=51).

Characteristics	n(%)
Marital status	
Single	3(5.9%)
Married	40(78.4%)
Separated/divorced	3(5.9%)
Widowed	5(9.8%)
Educational level	
Primary school	33(64.7%)
Secondary school	15(29.4%)
High school	1(2.0%)
University	2(3.9%)
Current occupation	
Employed	6(11.8%)
Unemployed	5(9.8%)
Retired	40(78.4%)
GOLD classification	
Mild to moderate	20(39.2%)
Severe to very severe	31(60.8%)

Table 2 - Activities and Participation ICF categories identified from the participants' interviews.

ICF code	ICF category identified	Corresponding second level categories
d230	**Carrying out daily routine**	
d240	**Handling stress and other psychological demands**	
d2401	Handling stress	d240 Handling stress and other psychological demands
d330	**Speaking**	
d3503	Conversing with one person	d350 Conversation
d4100	Lying down	**d410 Changing basic body position**
d4101	Squatting	d410 Changing basic body position
d4102	Kneeling	d410 Changing basic body position
d4103	Sitting	d410 Changing basic body position
d4105	Bending	d410 Changing basic body position
d4150	Maintaining a lying position	d415 Maintaining a body position
d430	**Lifting and carrying objects**	
d4300	Lifting	d430 Lifting and carrying objects
d4301	Carrying in the hands	d430 Lifting and carrying objects
d4302	Carrying in the arms	d430 Lifting and carrying objects
d4303	Carrying on shoulders, hip and back	d430 Lifting and carrying objects
d450	**Walking**	
d4500	Walking short distances	d450 Walking
d4501	Walking long distances	d450 Walking
d4502	Walking on different surfaces	d450 Walking
d4552	Running	**d455 Moving around**
d4551	Climbing	d455 Moving around
d4600	Moving around within the home	**d460 Moving around in different locations**
d4602	Moving around outside the home and other buildings	d460 Moving around in different locations
d4750	**Driving human-powered transportation**	**d475 Driving**
d4751	Driving motorized vehicles	d475 Driving
d510	**Washing oneself**	
d5100	Washing body parts	d510 Washing oneself
d5400	Putting on clothes	**d540 Dressing**
d5402	Putting on footwear	d540 Dressing
d550	Eating	
d5702	Maintaining one's health	**d570 Looking after one's health**
d6200	Shopping	**d620 Acquisition of goods and services**
d630	Preparing meals	
d640	**Doing housework**	
d6400	Washing and drying clothes and garments	d640 Doing housework
d6401	Cleaning cooking area and utensils	d640 Doing housework
d6402	Cleaning living area	d640 Doing housework
d6403	Using household appliances	d640 Doing housework
d6500	Making and repairing clothes	**d650 Caring for household objects**
d6501	Maintaining dwelling and furnishings	d650 Caring for household objects
d6505	Taking care of plants, indoors and outdoors	d650 Caring for household objects
d660	**Assisting others**	
d6600	Assisting others with self-care	d660 Assisting others
d7202	Regulating behaviours within interactions	d720 Complex interpersonal interactions
d750	Informal social relationships	
d760	Family relationships	
d7600	Parent-child relationships	d760 Family relationships
d770	**Intimate relationships**	
d8451	Maintaining a job	**d845 Acquiring, keeping and terminating a job**
d850	**Remunerative employment**	
d920	**Recreation and leisure**	
d9201	Sports	d920 Recreation and leisure
d9205	Socializing	d920 Recreation and leisure

ICF categories included in the Activities and Participation component of the ICF Core Set for OPD are shown in bold typeface.